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Mr. Rod Mickleburgh,
Health Policy Reporter,
The Globe and Mail,
444 Front St.,
Toronto, Ontario.

M5V 2S9

24 September 1991

This is not a letter to the editor

Dear Mr. Mickleburgh,

Perhaps, in the end, you will continue to dismiss me as just another dissatisfied member of an interest group, but I must again appeal to your professionalism, to your sense of fairness, and once again ask that you include our position, or at least some of the facts it is based on, in stories affecting the interests of our members.

The Grope and Flail has been asked several hundred times during the Decade of Disabled Persons to stop referring to sensitivities as "twentieth century disease", unless, of course, you mention that the term is a misnomer. The problems have existed for generations. They've been researched by mainstream medicine for more than a century.

Contrary to the impression left by the article (which re-iterates the Ministry of Health's framing of these issues) there has been a lot of research. It not hard to find medical references, if you look for them. An hour after I was diagnosed in 1979 I was in Carleton University's library reading an article published in 1951. In 1987 Health and Welfare published a 244 page bibliography of articles with references to environmental sensitivities dating back to 1908. Ashford and Miller (1989) mention a study in 1880.

Environmental sensitivity (sometimes called "chemical sensitivity", or "intolerance") is not "an illness". Sensitivities can be caused by various illnesses, some treatable, others for which the only relief is by avoidance. The immune system is only sometimes involved. What these illnesses have in common is that they leave people reacting to natural and synthetic compounds they are sensitive to (or "do not tolerate well"), at levels of exposure that don't seem to affect the majority.

There is controversy in mainstream medicine. It is about how to categorize the various illnesses, how to tell which illnesses an individual person is suffering from (diagnosis), and how to treat them. Many sensitivities are diagnosed by accepted methods of medical practice.

Some Ministry of Health officials rationalize their abuse of persons with sensitivities with illogical and unethical statements, including the bold-faced lie that doctors do not generally agree that much can be done with existing and officially recommended medical techniques.

It might help you to understand the Ministry of Health's dilemma by understanding its parallel with Mount Cashel, where abuse continued because the authorities would not acknowledge their negligence in not responding to previous complaints of abuse. Unfortunately, if the Ministry of Health is to come clean on these issues it will involve an implicit acknowledgement that the actions of some parts of the Ministry, which are causing millions and millions of dollars damages, increased disabilities, and deaths, are not only damaging but grossly irresponsible.

Most medical associations, all health consumer groups believe it is unethical to call people's reputation for

soundness of mind into question solely on the basis of an absence of information, in this case an ignorance of the physiology involved in understanding some types of sensitivity reactions, particularly those where the central nervous system is affected. It is unethical to call people's reputation into question on the basis of their membership in a disabled group.

It is unethical when authorities (or journalists) tolerate such practices.

Up until very recently, the people mandated to help us have instead added insult to injury. In most cases the insult was more damaging than the disability itself. Families broke up, when one spouse decided, on the basis of advice sanctioned by the Ministry of Health, that the other was just not trying. Professional reputations and careers have been ruined.

Although there have been significant improvements throughout most of medicine, occasionally people have been caused increased disability when their sensitivities have been dismissed as "all in the mind". There have been several deaths, some of them suicides of people similarly abused by government officials.

The primary issue is not recognition, as suggested by the sub-head. Recognition that there are illnesses which are causing environmental sensitivities, that these are legitimate complaints, and that consequent social needs are legitimate, has not been the issue in this province for several years. The Grope and Flail has been repeatedly advised of this. The idea that we are "fighting to get our illness recognized" is seriously misleading, a disservice both to ourselves and to medicine (not to mention your readers).

If we were fighting for recognition, as the line from the Ministry of Health and the Globe and Mail goes, who would we fight? Who would be our targets? Perhaps the following groups?

1. World Health Organization, which has given a Macedo Award for the work of Dr. Nicholas Ashford and Claudia Miller (Dec, 1989) for the New Jersey State Department of Health (not covered by G&M).

2. Canadian Public Health Association, which included a paragraph on the concern in their submission to the federal Green Plan in 1989 (not covered by G&M).

3. Ontario Public Health Association, which sponsored a conference on the subject in May 1987 (not covered by G&M), and is including the issue in it's upcoming annual conference this fall (<u>in part to encourage the Public Health Section of the Ontario Ministry of Health to get the lead out</u>).

4. The Canadian Medical Association, which took part in the Laboratory Centre for Disease Control workshop (May 1990, Report distributed April 1991, neither covered by G&M), is distributing information to doctors about the concern, calling for more research to help doctors <u>better</u> deal with the problems.

5. The Ontario Medical Association, which has had a policy paper on environmental sensitivities since 1987 (not covered by G&M) which recognizes that people "are ill" with an illness that is "not well defined scientifically" and that in the

meantime we should "avoid blaming the victims". They know there's an attitude problem involving a minority of doctors in the medical community, and it was with that in mind that their past president sent a letter of congratulations to a conference (April 1990, not covered by G&M) sponsored by our organization and the Ottawa-Carleton District Health Council, and published items in the Ontario Medical Review in March and July of this year (which you refused to obtain or include in your coverage).

6. Several federal departments and agencies, including:

(1) Revenue Canada (tax deductions for medical expenses granted 1989) (not covered by G&M),
(2)Treasury Board (air cleaners for public servants affected since 1986),
(3)Environmental Canada and Secretary of State (sponsored the first national conference of people affected, Ottawa, April 1987) (not covered by G&M),
(4) Transport Canada (invited discussion on accessibility in inter-provincial transport, 1987),
(5) Consumer and Corporate Affairs (invited discussions on food product labelling, 1986),
(6) Employment and Immigration (invited discussions on Jobs Strategy measures to help persons with disabilities re-enter the work force and employers become more familiar with our concerns, 1991),

(7) Canada Mortgage and Housing Corporation (provide home renovation grants under RRAP program to assist persons disabled by substances in their place of residence, also air quality and health studies in connection with the issue, since 1984) (not covered by G&M),
(8) Canadian Centre for Occupational Health and Safety (keeps materials on file in connection with occupational considerations and self-help groups) (not covered by G&M),
(9) Canadian Human Rights Commission (public statements, 1988, 1990, concerning the humiliation suffered by this group due to misconceptions) (not covered by G&M),
(10) Government House (invited representatives as part of celebrations marking National Access Awareness Week, 1991) (not covered by G&M),
(11) Health and Welfare (provides CPP disability pensions to people disabled by environmental sensitivity, (since 1985) sponsored workshop on sensitivities (May 1990) and distributed report of proceedings (April 1991) to 15,000 doctors and to provincial ministries of health, social services, housing, disability issues, and human rights commissions, sponsoring research on diagnostic and treatment protocols and epidemiology). <u>This work was pressed for precisely because provincial Ministries of Health are abusing persons</u>

with this disability. (not covered by G&M),

(12) National Library (invited selection of related materials in Library for the Disabled, 1991),

(13) Public Service Commission of Canada (includes persons with environmental sensitivities in disabled employment equity bank since 1986) (not covered by G&M),

(14) Statistics Canada (included environmental sensitivities in post censual survey of disabled, 1986) (not covered by G&M),

(15) Supply and Services Canada (agreed to include concerns of environmentally sensitive in environmentally friendly product procurement process of federal government, 1989) (not covered by G&M)

7. Several provincial ministries and agencies, including:

(1) Ontario Human Rights Commission (publicized case resolved 1 Feb 1990, (not covered by G&M), offered to three consecutive Minsters of Health to help address attitude problems in the community (not covered by G&M)).

(2) Ministry of Health, (sponsoring research on environmental sensitivities, consultations for physicians unfamiliar with the problem) (but still obfuscating issues with the help of the Grope and Flail, and defending past and current unethical abuse).

(3) Ministry of Housing (provides OHRPD grants similar to CMHC since 1987, in situ rent supplements for persons on welfare who need special housing subsidies for private stock accessible to them, funding for the construction of public housing accessible to persons with this problem, 1990) (not covered by G&M),

(4) Ministry of Community and Social Services (provides FBA under disability provisions, provides diet supplements, disability benefits since 1983, although inconsistently) (not covered by G&M),

(5) Ministry of Education (sensitivities "should be included as a possible cause" when assessing learning and behaviour disabilities in school children, Marion Boyd, 1991) (not covered by G&M),

(6) Ministry of the Environment ("The environmentally sensitive are the first to feel the adverse effects of pollution" - Jim Bradley, 1987, environmental inspectors help with special needs in connection with water supply and pesticide use) (not covered by G&M),

(7) Ministry of Natural Resources (confiscated wild game as source of chemical free meat since the 1970s) (not covered by G&M),

(8) Ontario Provincial Police, Ottawa Valley Detachments, (notification of road kills as source of organic meat, in some cases help with timely bleeding of

animals at the scene of accidents) (not covered by G&M),
(9) Worker's Compensation Board (some cases in our favour),
(10) Solicitor General (Chief Coroner made suggestions (Oct 1989) in connection with suicides related to attitude problems in minority of doctors and public after the last of several suicides brought to his attention.)
(Excellent coverage by Christie Maclaren)

Who would the Globe and Mail have us lobbying for recognition? Whose support would convince you, Dr. Mickleburgh? You would have us eradicate all bigotry on the planet? It's not going to happen. Give your head a shake!

On the phone you said the Ministry of Health said we were fighting for "recognition". Surely, sometime, you will adopt a healthy scepticism about what the Ministry of Health tells you. Surely you haven't become "married to your sources"?

The primary issue is not scientific research. The issue is how people act while not omniscient, which is likely to be for some time. Arbitrary discrimination in the provision of health care to members of this disabled group, the unspoken subject of your story, is an important part of this concern.

A secondary issue is the integrity of the Ontario Ministry of Health and other provincial health ministries, something the new Health Policy Reporter at The Globe and Mail finds impossible to question.

Take, for instance, the fact that it was the Chairman of the Ministry committee on sensitivities, Harvey Anderson, who referred you to Leznoff. Leznoff's views are, as you know, based on an absence of information. His arbitrary presumption is "on the wrong side".

A damaging opinion which is based solely on an absence of information is unethical no matter how splendid the emperor's clothes. This is where your paper's credo becomes relevant. "The subject who is fully loyal to the Chief Magistrate will neither advise nor submit to arbitrary measures".

Damaging opinion based on an absence of information is referred to as "arbitrary" by thinking people. You, of all people, are supposed to be able to see through the (health) emperor's clothes. You are supposed be able to protect your readers from arbitrary damaging opinion, even when it comes from a (tragically out-of-touch) emperor.

If someone heading a ministry committee articulating the concerns of hyphenated Canadians, for instance services for African-Canadians, were to refer you to Phillip Rushton for a point of view, either you would ignore it as an irrelevancy, or the fact that the committee chairman did this would become a major part of the story. Instead, you put forward Leznoff's opinion as if it represented "traditional medicine".

You had been warned that well-intentioned people like Anderson defend legitimate criticism of supportive medical theories by suggesting that critics of physician's theories are really denying our experience.

Lamentable bigots like Leznoff, Stewart, and K.G. Marshall, of Montreal, confuse legitimate criticism of

postulated theory as being a denial of reality (as experienced by persons with sensitivities and as approached by mainstream medicine). Putting forward his view as the pulse of "traditional medicine" would be laughable, except for the potential damage of doing so.

If you'd checked, as I pleaded with you to do, you would have found that Leznoff's views are shared neither by his hospital or the Ontario Medical Association. You might have connected with some of the medical and health authorities mentioned in the list above, if you had wanted to know what "traditional medicine" is saying.

If you had checked, you might have confirmed what I told you, that the Ontario Medical Association has written the former Premier's Office, decrying the fact that "social needs are not being met" and indicating the OMA position, which is that "people are ill with a condition that is not well defined scientifically", and that in the meantime "it is important to avoid blaming the victim".

The money Professor Anderson is handing out for research was made available after the OMA wrote the Premier's office pressing for such funds to made available. Your readers might have read Anderson's comment that "traditional medicine says 'Why spend money on something that doesn't exist?'" differently if they'd known this. I wonder how the OMA views his self-congratulatory comment - "But in my view we owe society an investigation of what's causing this, it's the responsible thing to do" - after pressing for the funding Anderson is handing out?

Is it possible that you have miss-represented the views of Anderson as well as those of mainstream medicine? We'll have to ask him.

Why did you refuse to call the Ontario Medical Association when I pleaded with you to do so, when I told you that the arguments, especially those concerning mainstream medicine, were being confused by the Ministry of Health?

Surely the opinions of Leznoff should not be put forward as representing mainstream medicine. Surely the illogical and unethical nature of his comments should be revealed.

Ask a medical ethicist you trust, "is it responsible to label a person as mentally ill solely on the basis of an ignorance of the physiology involved in their complaint?" Ask a scientist if it is scientific to assume there is no physiological basis for central nervous system reactions, simply because you are unaware of any.

Ask both whether it is ethical for physicians to use the credibility of their patients' experience as cannon fodder for criticism of their theories, whatever those theories may be. Ask the Chief Commissioner of the Ontario Human Rights Commission if it is ethical to make damaging statements about people on the basis of their membership in a disabled group.

And please inform you readers of their opinions.

If you are doing another story about the Ministry of Health's discrimination in providing health care to members of this disabled group, there's something else you know about that you might mention: It was because so many people were in Marilyn McCleary's position that the Ontario Minister of Health appointed a committee on this subject in 1984. If you are going to report the ravings of Leznoff, who blames the media for making us crazy, you might have reported that Thomson and his doctors stated outright that it is "clearly

untenable" to state that our problems are all caused by emotional illness.

Balance in journalism?

The Committee, comprised of doctors and headed by former Provincial Court Judge George Thomson, (who is now Deputy Minster of Labour 416-326-7606) made several recommendations in 1985 about what the province should provide in the way of health care to people like Marilyn.

You seem to have internalized the Ministry of Health's framing of issues, at the expense of fairness, at the expense of a balanced expression of what is going on. For instance, you reported the Ministry of Health's claim that they have "done all we can" to help McCleary without reporting that they have implemented none of the recommendations concerning health care made by Thomson and his panel of doctors.

You mention that the report from the workshop sponsored by the Laboratory Centre for Disease Control states that these problems "warrant further study". It is probably inadvertent, but this, too, reinforces the Ministry's "we need more research" routine, without balancing that perspective by mentioning that there is a huge amount of research already, and that there are many current medical practices that can be used to help most (although not all) people with these problems.

If you want the pulse of mainstream medicine, instead of bigots whose comments are colourful simply as a function of their abusiveness, you might have reported that the politician most responsible for moving Health and Welfare forward is a former "Family Physician of the Year" and would, I'm certain, win all (reasonable) parties' acceptance as representing

"traditional medicine". I'm referring to Dr. Bruce Halliday, M.P. a Conservative from Ontario. Why didn't you choose him to represent "traditional medicine" instead of Leznoff? Was it arbitrary? Or deliberate? Were you practising journalism, or simply passing on the Ministry of Health's biased framing of the arguments?

You knew the LCDC workshop was attended by mainstream medicine, and that the presenters were all from mainstream medicine. It would have cast a different light on what you did chose to include if your readers had known this.

The workshop also recommended that "patients should not be dismissed as neurotic" and "physicians interested in the problem should not be stigmatized". You knew of these recommendations. Did you not think them relevant to Leznoff's ravings, or would this, too, have destroyed your theme of "nonsense", "hostile reaction" and "hocus pocus"?

Your readers might have viewed Dr. Marshall's letter (19 September, The Globe and Mail) differently, if they had read the LCDC workshop statement saying labelling such as his - "adds considerably to the suffering of patients and their families". This is true whether it is done in the clinical setting, or in Canada's pre-eminent newspaper.

Sometime The Globe and Mail might report that Health and Welfare considered the issue important enough to distribute the LCDC workshop report to all provincial ministries of health, housing, social services, offices for disability issues, and human rights commissions, and to 15,000 physicians, an uncommonly huge distribution (five times greater than usual for the publication it was released in).

Would you ask yourself, as a Health Policy Reporter, why it was necessary for the federal department to make this public and pervasive sortie into an area considered to be under provincial jurisdiction? Is it possible they know the provinces are abusing people, that they need a (polite and gracious) kick in the butt?

The great sin of the environmentally sensitive is that we <u>have</u> been abused by the very authorities officially mandated to help us, the provincial Ministries of Health. Instead of acting in a forthright manner on evidence that has existed for decades, provincial health authorities across the country are obfuscating the issues, saying the problem is new when it's not, denying the existence of a huge body of medical literature, and denying support in mainstream medicine years after mainstream medical associations have pressed for action.

Unfortunately, some doctors who want to be supportive and some journalists with only a superficial understanding of what's going on have been unconscious partners in creating and maintaining this smoke screen.

The Ontario Ministry of Health knows full well it is unethical to call people's reputations into question on the basis of an absence of information, yet they use the fact that it is done in some dark corners as a reason for not stopping their own abuse of us. The abuse is being carried out by the Ministry of Health, while condemned by science and mainstream medicine, and while the Ministry of Health claims to be doing "all we can do". Doesn't that say anything to you about Health Policy in this province, or on this issue? Doesn't that tell you something about your sources?

As long as the presumption is on the wrong side, the Ministry of Health and others can continue to abuse our human

rights, discriminating in the provision of services, leaving us objects of harassment, of arbitrary interference, and of abuse in Ministry facilities.

As long as journalists focus on an unreasonable debate that has been set aside by reasonable parties years ago, that was fuelled by arbitrary statements and "by stories in the media that concentrate on extreme positions" that are "clearly untenable" (Thomson), that calls our experience as human beings (and citizens) into question on the basis of an absence of information, that is only possible if you arbitrarily dismiss hundreds of medical articles dating back more than a century, the more serious issues, such as the abuse by health ministries in all provinces of persons whose central nervous system dysfunction is caused by sensitivities or the abuse by school boards of children with learning and behaviour problems caused by sensitivities, are not being addressed in a forthright manner.

As long as journalists write articles that confuse rather than illuminate, that misrepresent the fight we're involved in such a way as to make marginal opinion seem mainstream, and to make our basic concerns, which are supported by the mainstream, seem marginal, those of us who are extremely busy fighting this fight will be distracted by the need to turn back and wipe up after people such as yourself who are paid (good money) to do better.

We have enough problems with the fact that the Ministry of Health is misleading people as to what <u>our</u> issues are without you taking on <u>their</u> expression of what <u>we</u> are after. Do you contact management to find out the union's demands?

As long as Hugely Perfect Reporters presume to know more about the arguments than we do, we cannot rely on the media

to provide others with a clear explanation of the disability, the consequent special needs, the issues related not only to discrimination in the provision of services but also those arising from seriously damaging abuse of persons with this disability by Ministries of Health, or even to relate our significance to society in general.

Sincerely,

Chris Brown
President, Ottawa Branch
(613) 837-7173

(attachments)

cc National Editors
John Cruickshank
Tim Pritchard
Bill Thorsell
Queen's Park Legislative Research Service
John Krauser (OMA)
Dr. John Davies (LCDC)
Professor Harvey Anderson (UofT)
Dr. Gerald Ross

P.S. You might keep in mind your future coverage of issues related to environmental sensitivities that the fight in the United States is about four years behind ours here in Canada. What Thomson and his panel of doctors found in Ontario in 1985, Ashford and Miller reported to the New Jersey State Department of Health in 1989.

The Americans won a World Health Organization award for their work. The Canadians had their report ditched by conniving in the Ministry of Health. (A couple of current Ontario cabinet ministers complained about what was done at the time.)

One of the great concerns of persons with sensitivities in Canada these days is the influence of American media in our country. Gains we have made in Canada are in jeopardy because of the less advanced state of affairs in the U.S., combined with the excessive influence of U.S. journalism here.

Incidently, please keep in mind that medical associations represent doctors. Over the past couple of decades, doctors in Canada and the United States have killed hundreds of people with sensitivities. Would you have any thoughts about how that might affect the position of organizations representing doctors, even those who want to end the damages, increased disability, and deaths still being caused, albeit by a minority of their members?

The Globe and Mail, Thursday, September 5, 1991

HOSTILE REACTION / *While victims of 20th-century disease*

fight to get their illness recognized, some doctors say it's all nonsense

Living in pain and isolation

BY ROD MICKLEBURGH
Health Policy Reporter

STARING gloomily at the outside world through a screen in her darkened bungalow, Marilyn McCleary tries to recall what her life was like before it became a living hell.

Mostly, she remembers simple things: "Being with my family and my son, Scott. Sitting down for a meal together. The pleasure of watching TV. And going for a walk. Hearing the birds, feeling the fresh air, stopping to talk to a friend. When you lose everything, the ordinary things are what you miss the most."

These days, Ms. McCleary, 45, can barely get out of bed. She is the victim of a bizarre, poorly understood condition known as multiple chemical sensitivity.

For reasons that medical science has yet to explain adequately, Ms. McCleary is unable to tolerate even the low levels of chemicals contained in the air and most everyday items.

"I get terrible spasms, chest and heart pain, my legs and arms go numb," she said. "I'm dealing with problems from morning till night, trying to survive in a world that isn't very nice to me. I feel like the Tin Man in *The Wizard of Oz*. I need a good can of oil."

Sometimes called environmental illness or 20th-century disease, multiple chemical sensitivity continues to spawn controversy. Some doctors denounce it as nothing more than hocus-pocus, and those stricken often face a disheartening struggle for recognition of their condition as a legitimate illness.

In the case of Ms. McCleary, who lives in Barrie, about 100 kilometres north of Toronto, the Ontario Health Insurance Plan will cover only part of the extensive costs of treatment at a specialized, environmentally controlled hospital in Texas, even though no such facilities exist in Canada and doctors say she is in desperate need of treatment.

The Health Ministry regards the hospital's treatment as experimental and is therefore unwilling to pay for more than 75 per cent of the hospital's $1,000-a-day charges. That leaves Ms. McCleary unable to afford more than two months of the six-month stay that her doctors believe is necessary.

"It's a sad situation, the saddest case that we have," said Girma Yohannas, a ministry spokesman. "We have tried our best to do what we can for her, but we can only do what is possible to be done."

Please see ILLNESS—A4

Illness apparently triggered by chemicals

• From Page A1

Ms. McCleary believes that this is unfair. "What is so stressful is that I'm so ill I've no stamina, yet I can't get the same care that cancer and heart patients get. It seems that with this illness you have to fight for everything you get."

The distressingly thin former nurse has been enduring a grim, prison-like existence for the past 10 years, cut off from normal pursuits, her frail body racked with pain.

Her diet is restricted to a few organically grown products. She cannot tolerate visitors or go outside. Even ordinary activities become torturous rituals.

Telephone conversations must be relayed through her 82-year-old mother, who climbs the stairs between Ms. McCleary's room and the basement telephone.

Last Christmas, her son stood outside in the snow, opening her presents, as Ms. McCleary watched through the window, unable to risk exposure to the wrappings. An interview is conducted in a similar manner, with the reporter outside talking to Ms. McCleary through the window screen.

WORST of all, she has a form of the illness that also produces severe reactions to vibrations from common appliances, such as the refrigerator, stove, furnace, radio, television or a neighbour's lawn mower.

"People who are well don't notice these currents at all. But it's like being plugged into a socket. It goes 'zit, zit' up my legs and into my spine. Even the noise of equipment affects me."

Her mother, Dorothy Giddy, said: "You might say Marilyn is not able to cope with living in general. It's closing in on her. Her body simply isn't able to cope with what you and I take for granted."

Gerald Ross, a Canadian specialist in environmental illness who examined Ms. McCleary in the spring, said her condition is both serious and rare.

"Her degree of problems constitutes between 3 and 5 per cent of all patients with environmental illness. She's very weak, severely malnourished, emotionally and physically exhausted," Dr. Ross said.

"On a scale of 1 to 10, I would put her situation at 9. She's in pretty bad shape, one of the worst I've seen."

Dr. Ross said Ms. McCleary's problems appear to have been triggered by exposure to some toxic chemicals during her six years as an occupational health nurse at a paper manufacturing plant in Cornwall, Ont.

"What happens is that these people are perfectly normal until they are exposed to a specific chemical," he said. "Then, all hell breaks loose and they are never the same again."

Victims such as Ms. McCleary suffer from what Dr. Ross called "a spreading phenomenon" in which, over time, more and more substances evoke hostile reactions in the body.

But Arthur Leznoff, chief clinical immunologist at St. Michael's Hospital in Toronto, angrily dismisses any suggestion that environmental illness is a legitimate medical condition.

"We're dealing with nonsense here," he said. "This is hocus-pocus medicine, and you guys [the news media] are responsible for these people with your irresponsible, sensational articles."

Dr. Leznoff said people like Ms. McCleary perceive that they have toxic reactions to chemicals, resulting in hyperventilation and "panic attacks," and that is what produces the headaches and numbness.

"It's much more acceptable to say you have an organic disease than a psychiatric disease," he said. "They're making a non-disease into a disease.

"What's going on is a real question, but until we have some serious answers, we can't go around calling this a syndrome."

Both the Ontario and federal governments have launched investigations into the disorder.

A workshop held last year by the federal Health and Welfare Department in Ottawa concluded that multiple chemical sensitivity was worthy of serious scientific study. It recommended that, in the meantime, patients not be denied social benefits because of the ongoing medical debate.

"Benefits should be based on defined functional disabilities, not on the medical label," the workshop's executive summary said.

Harvey Anderson, acting chairman of Ontario's committee on environmental hypersensitivity, said the committee hopes to finance four pilot projects on the disorder.

"Traditional medicine says, 'Why spend money on something that doesn't exist,' but in my view, we owe society an investigation into what is causing this. It's the socially responsible thing to do," said Mr. Anderson, a nutritional scientist at the University of Toronto.

Marie Laurin, national president of the Advocacy Group for the Environmentally Sensitive, said that as many as 20,000 Canadians are affected by some form of environmental illness, although fewer than 20 as badly as Ms. McCleary.

"The system is not answering the needs of the severely ill," she said. "It's more than time that governments opened treatment centres here in Canada."

But Ms. Laurin added that treatment, though important, is not always the answer. "It's also good to try to take your life into your own hands, to stop being afraid and try to end what may sometimes be paranoia about chemical reactions," she said. "Many survivors end up doing their own healing."

Meanwhile, Mrs. Giddy wrestles with trying to get legal help to continue long-standing efforts to win disability and workers' compensation benefits for her daughter, and scraping up enough cash to pay for treatment at the new environmental control unit of Tri City Hospital near Dallas, one of the few institutions in the world to specialize in people with multiple chemical sensitivity.

IN the unit's specially designed atmosphere where chemical exposure is carefully limited, Ms. McCleary's resistance would first be built up through a nutrient-enriched diet administered intravenously.

After that, an exhaustive series of tests would be carried out in an effort to expand the range of medication and food she can tolerate.

"She will be better nourished, her immune system will be improved and so will her detoxification abilities," Dr. Ross said. "She needs to get out of the house she is in now, which is very moldy. In these cases, just avoidance of chemicals is treatment. It enhances the body's resistance."

OHIP financed a previous visit to a similar unit in Dallas by Ms. McCleary in 1986, and plan officials agree that she returned in much better health.

But this time, Ms. McCleary and her mother will have to make up much of the money themselves.

"We're really worried our funds will run out after two months and that just isn't enough time," Mrs. Giddy said. "We know it's a lot of money for OHIP, but they do all sorts of coverage for cancer patients. We think it's discrimination. How could you look at Marilyn and say she's not ill?"

IX - The Professional Debate

As a Committee, we have become increasingly dismayed at the polarized and adversarial positions being taken in the United States on the issue of environmental hypersensitivity. Our unease has been increased by the realization that there is evidence, although fortunately not yet extensive, that the same hardening of attitudes is taking place in Ontario, often fueled by media reports that highlight the extreme positions referred to elsewhere in ths chapter. The toll, emotional and financial, on those involved in disputes in the United States was apparent to us; increasingly the conflict seems to be moving into the courtroom.

We believe that confidence in the health system is eroded when productive dialogue between different medical specialties disappears or is replaced by acrimonious debate before a confused public. Protagonists take up positions that are clearly untenable: eg., "all medical treatments are based upon sound scientific research"; "the environment plays little role in the generation of disease"; "all the identified patients are emotionally ill". Research that is clearly unsound methodologically is given greater weight than it deserves. There is a tendency to assert the validity of one's position on the basis of the quantity, not the quality, of the clinical trials that have been undertaken. Success is measured in the name of the latest clinician or researcher to cross from one side to the other.

The committee feels strongly that taking an absolute stance in this field is not only risky scientifically, given that there is a great deal we do not know about our environment and its effects on us, but it is also unproductive and divisive, antithetical to the task of promoting collaborative efforts that will help in understanding and treating the problem of a growing number of patients.

We emphasize again the need to develop approaches that bring together all practitioners, however their perspectives differ, and to do so before the gulf between them becomes as great as it now appears to be in the United States.

Thompson Report on Environmental Hypersensitivities
pp266, 267.

BRIEFING INFORMATION ON

ENVIRONMENTAL HYPERSENSITIVITY

Background

- Environmental hypersensitivity is a disorder involving multiple sensitivities to a wide range of foods and chemicals in the environment at levels generally tolerated by the majority. The immune system is often but not always involved and additional symptoms may be manifested directly on the nervous and/or other bodily systems.

- Due to the difficulties of diagnosis and identification of the causes, as well as the non-specific nature of many of the symptoms, there has been much controversy in medical circles over whether the illness is in fact a real disease. Some practitioners have ascribed symptoms to psychosomatic causes.

- In Canada, medical questions to do with diagnosis, treatment and associated costs of illness are clearly under provincial jurisdiction. The Province of Ontario has dealt with the issue by appointing the Thomson Committee to investigate and make recommendations. The Thomson Report was released in December 1985 and a second committee chaired by Dr. B. Zimmerman has reviewed the recommendations and released its report on December 19, 1986.

- Both the Thomson Report and the Zimmerman Review reported that, although there was debate as to the nature, diagnosis, causes and prevalence of the illness, there was no doubt that some people suffered illnesses ranging from mild discomfort to severe disability. The Ontario government has, therefore, called for research proposals on prevalence of the disease and for controlled studies on appropriate methods for diagnosis and treatment.

Relevant Factors

- The Minister of National Health and Welfare has received at least six letters seeking support concerning hypersensitivity from one correspondent, Mr. Chris Brown, as well as about ten letters by the same correspondent referred from other federal Ministers.

Departmental Position

- The Minister has indicated that, while he is sympathetic to the cause of those with environmental hypersensitivity, the area is largely under the jurisdiction of the provinces. However, the mandate of the Department of National Health and Welfare also includes responsibilities for the control of chemicals in food, air and water. The Minister has also outlined our commitment to programmes in areas concerned with pollution abatement.

Mrs. Grace Wood (957-1503)
Health Protection Branch
January 12, 198/: 4:00 p.m.

88-30825
1126-2-07

AUG 3 1988
AOÛT

Canadian Human Rights Commission
Commission canadienne des droits de la personne

Chief Commissioner
Président

The Honourable Jake Epp, P.C., M.P.
Minister of Health and Welfare
Brooke Claxton Building
Tunney's Pasture
Ottawa, Ontario
K1A 0K9

My dear Minister:

The Commission has recently been contacted by Mr. Chris Brown, with whom I think your office may already be familiar. Mr. Brown suffers from environmental hypersensitivity, and is concerned that the nature of that complaint has not been sufficiently recognized by government authorities and that this, is turn, has added to the social and professional hardships which he and other sufferers from this condition are subject to.

Some years ago, Mr. Brown lodged a complaint with the Canadian Human Rights Commission; the Commission did not feel the complaint could properly be dealt with under the Canadian Human Rights Act. I am sure it was not the Commission's intention at that time to question the authenticity of Mr. Brown's condition. It is my understanding that environmental hypersensitivity is a true medical problem, and that we owe it to people who have the misfortune to suffer from this syndrome to be more public and more positive in acknowledging that fact.

As you know, Mr. Brown recently brought his concerns to the Standing Committee on National Health and Welfare, where he received a sympathetic hearing (HC Issue No. 48, May 26, 1988). On that occasion, he expressed the hope that the Health Minister would state publicly that he is sympathetic to the plight of those who suffer from environmental hypersensitivity and considers their concerns legitimate.

My purpose in writing to you is simply to let your know that we consider this request a reasonable one and that anything your department can do to increase public awareness of the legitimate concerns of people like Mr. Brown would, in our view, be most useful.

CO	MIN	DMO	E.A.	DCFR

ack
ORIGINAL TO: HPB

+ see also p.c. from S. Copps.

Yours sincerely,

Maxwell Yalden

90 Sparks Street, Ottawa, Ontario K1A 1E1
90, rue Sparks, Ottawa (Ontario) K1A 1E1

HOUSE OF COMMONS

Issue No. 23

Thursday, May 10, 1990

Chairman: Bruce Halliday

CHAMBRE DES COMMUNES

Fascicule nº 23

Le jeudi 10 mai 1990

Président: Bruce Halliday

Minutes of Proceedings and Evidence of the Standing Committee on

Human Rights and the Status of Disabled Persons

Procès-verbaux et témoignages du Comité permanent des

Droits de la personne et de la condition des Personnes handicapées

The Chairman: You have indicated that we need to stress the areas of aboriginal peoples and disabled people. I notice that you gave us an interesting list of the wide variation of issues that you are faced with. There was one exotic one that you did not mention: the problem of environmental sensitivity and how it causes disabilities. I am wondering if you would offer any comments on how you feel that this affects disabled people and to what extent you are in a position to do something to offset the medical and social effects of these conditions.

Mr. Yalden: I and my colleagues find it is a regrettable situation that surrounds the matter of environmental sensitivity. There is a tendency in many circles to write it off, to treat it as though it did not exist. They shake their heads; they say there is just no dealing with some people. Our attitude, however, is that it is a problem, a genuine problem. It is a problem from which some people suffer, and suffer very painfully. They suffer the more because of this element of humiliation. No one will take them seriously. We believe that there is a degree of public misunderstanding, and we would like to try to see that redressed.

We will investigate complaints from any person who believes that he has been discriminated against because of suffering from environmental sensitivity. It is not for us to pronounce on the medical issues involved—and there are medical issues. There is some degree of disagreement or lack of unanimity in the medical community as to what exactly is involved in this syndrome. We think it is very clear that it is an illness; it is a problem. It is not illusory. I think we all have a duty to try to help people to understand what is involved and to do something about it. Our commission is pleased to do that and pleased to take complaints, if we get them.

• 1620

Le président: Vous avez dit qu'il faut s'intéresser particulièrement aux autochtones et aux handicapés. Je vois cependant, dans la liste très intéressante des multiples questions auxquelles vous êtes confronté, un sujet assez bizarre dont vous n'avez pas encore parlé: celui des allergies environnementales, qui ont un effet débilitant. Pouvez-vous nous donner des précisions sur ce phénomène? Quelles solutions peut-on proposer?

M. Yalden: J'estime que la manière dont on traite aujourd'hui le problème des allergies environnementales est tout à fait regrettable car on a souvent tendance à l'ignorer, à faire comme si cela n'existait pas. On voit bien souvent des gens dire qu'il y a des personnes qui sont vraiment impossibles. Nous considérons quant à nous qu'il s'agit d'un problème réel, qui peut provoquer de graves souffrances à certaines personnes, d'autant plus graves que s'y ajoute ce facteur d'humiliation. Personne ne les prend au sérieux. A notre avis, le problème est mal compris du public et nous voudrions y remédier.

Nous ferons enquête chaque fois qu'une personne déposera une plainte disant qu'elle a fait l'objet de discrimination parce qu'elle souffre d'allergies environnementales. Il ne nous appartient pas de nous prononcer sur les aspects médicaux de la plainte. Je sais que tous les médecins ne sont pas d'accord quant à l'origine exacte de ce problème, mais il nous paraît très clair qu'il s'agit d'une maladie, pas seulement d'un problème. Ce n'est pas une illusion. J'estime que nous avons tous le devoir d'aider les gens à comprendre la nature du problème et à essayer d'y remédier. Notre Commission acceptera les plaintes qui lui seront adressées à ce sujet.

For Immediate Release
February 1, 1990

Further Information:
Alan Shefman
Director, Communications & Education
(416) 965-6841

HEALTH COUNCIL TO DEAL WITH **ENVIRONMENTAL HYPERSENSITIVITY**

The Ottawa-Carleton Regional District Health Council has recognized environmental hypersensitivity as a disabling physical condition, and will take positive steps to deal with the problem.

Environmental hypersensitivity is the subject of a complaint received by the Ontario Human Rights Commission, which has been settled recently.

The complainant, Chris Brown, defined environmental hypersensitivity as "an umbrella term referring to a group of sometimes disabling disorders caused by sensitivity to both natural and synthetic chemicals."

He claimed he had asked the Ottawa-Carleton Regional District Health Council to include the condition in the health planning process, but his request was ignored.

Mr. Brown, who has environmental hypersensitivity, then filed a complaint with the Ontario Human Rights Commission, alleging discrimination with respect to services, goods and facilities on the basis of handicap.

After a series of negotiations, a settlement has been achieved and approved by the Commission.

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103-045 (06/89)

According to Chief Commissioner Catherine Frazee, this is the first time a settlement of this nature has been reached.

"I am pleased to see that this issue can be resolved by using the **Human Rights Code**," she said, noting that the case is particularly important because the District Health Council agreed, as part of the settlement, to recognize environmental hypersensitivity as a disabling physical condition, and undertakes to deal with the issue constructively.

"Another positive aspect is that the settlement has been achieved through the joint effort and goodwill of the complainant and the respondent," she added, commending the contribution of Commission staff in facilitating this resolution.

The District Health Council will organize an educational workshop to discuss the nature and extent of environmental hypersensitivity, possible prevention and remedial measures, including treatment and accommodation issues, and the promotion of a wider understanding of the problem.

Various organizations in related fields, including the Academy of Medicine, the Human Ecology Foundation of Canada, and the Allergy and Environmental Health Association of Ontario, will be invited to take part in the workshop.

Mr. Brown has agreed to provide advice and comment during the planning of the workshop, to be held on April 6 this year. He will also address the executive members of the Ottawa-Carleton Regional District Health Council on the topic of environmental hypersensitivity.

He thanked the Ontario Human Rights Commission for achieving the settlement, and indicated that "it is a landmark case because it would reduce misconceptions about the issue, and help those with the problem in finding a solution."

-- 30 --

Ontario Human Rights Commission
Commission ontarienne des droits de la personne

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Toronto, Ontario
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12e étage
400, avenue University
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Chief Commissioner
Commissaire en chef

(416) 965-6847

April 23, 1991

Mr. Chris Brown
6267 Castille Court
Orleans, Ontario
K1C 1X4

Dear Mr. Brown:

I am writing to advise you that in response to your letter of November 2, 1990, I have conveyed to the Minister of Health, your views on the need for a concerted public initiative to educate the general population about the difficulties experienced by environmentally sensitive persons.

Given the uniqueness of the public perception and accommodation issues associated with environmental sensitivities, I have also offered our assistance to the Minister in shaping a better public understanding of a disability which is still widely misunderstood. I will also take every appropriate opportunity that may arise during the normal exercise of my responsibilities as Chief Commissioner, to draw public attention to issues related to environmental sensitivity as a disability.

I wish you and your colleagues success in your efforts to educate the public about the difficulties experienced by persons with environmental sensitivities.

Sincerely yours,

Catherine Frazee

Catherine Frazee
Chief Commissioner

/lw

2031-CB.LTR

Ottawa Citizen, 20 April, 1991, p. A-6

Report urges 'respect' for environmentally sensitive

By Tom Spears
Citizen environment writer

People whose health is affected by everyday pollution must not be "dismissed as neurotic," a major workshop sponsored by Health and Welfare Canada has decided.

The federal department is mailing thousands of copies of a report to doctors across the country urging "respect and support" for patients made ill by substances that don't bother most people.

"Knowledge of environmental sensitivities should be imparted to medical students and to practising physicians," the summary of the medical workshop says.

People with environmental sensitivities suffer a variety of symptoms from exposure to small amounts of common chemicals such as tobacco smoke, perfume, food additives and cleaning products.

The symptoms can range from migraine headaches and nausea to symptoms that resemble mental illness, said Chris Brown, president of the Ottawa chapter of the Allergy and Environmental Health Association. The group has about 300 members in this area who suffer from environmental sensitivities.

Brown said some doctors have refused to recognize environmental sensitivities as a health problem with a physical cause.

"They say we're crackers," he said. "The biggest problem we face, like many disabled groups, is a lack of understanding in the community."

Many environmentally sensitive people have been put in psychiatric hospitals when their behavior could have been treated by preventing their exposure to chemicals, he said.

"We're fantastically appreciative" of the report, he said.

The workshop's summary report says patients suffer even more when doctors imply "they are imagining their symptoms, or have some vague, untreatable mental illness."

And it says doctors interested in the problem suffer a "social stigma" in the medical community.

The May 1990 workshop had 48 delegates from the Canadian Medical Association, Health and Welfare, several provincial health ministries, medical schools and major hospitals. Other recommendations included:

- Setting up a central registry of doctors trained to treat the problem;
- Ensuring that insurance companies show "no discrimination against environmentally sensitive patients with regard to payment for medication, assistive devices and other illness-related expenses;" and
- Sending more information on the problem to "other groups of doctors besides allergists."

Ontario

Minister
Ministre

Ministry
of
Education

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de
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Édifice Mowat
Queen's Park
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May 27, 1991

Mr. Chris Brown
Branch President - Ottawa
The Allergy and Environmental Health Association
6267 Castille Court
Orleans, Ontario
K1C 1X4

Dear Mr. Brown

Subsequent to my letter of March 12, 1991, regarding this matter, it has been brought to my attention that you have requested further clarification of the Ministry of Education position regarding the status of environmental sensitivity within the exceptionality groupings included in the Ministry of Education Special Education Handbook, 1984.

The exceptionality groupings include descriptors which may be used to assist in the identification of pupil needs; they are not intended to be a complete list of medical illnesses. Although environmental sensitivity may not be one of the examples of causal factors listed in the descriptors, the ministry agrees that environmental sensitivity should be considered as a possible contributing factor in a learning disability or behavioural exceptionality.

Where environmental sensitivities are thought to be the cause of learning disabilities or behavioural difficulties, the identification of an exceptional pupil should include a review of the health needs as presented by both the parents and the medical practitioner. The identification, placement and review committee should consider the results of the health assessment in order to make its recommendations about the identification of the needs of the pupil.

.../2

I trust that this additional information is satisfactory. If you have any further questions or concerns, please continue to communicate with the officials in the Eastern Ontario Regional office, who will be able to assist you.

Yours sincerely,

ORIGINAL SIGNED BY.

Marion Boyd
Minister

Ontario

Ministry of the Solicitor General | Office of the Chief Coroner | 26 Grenville Street, Toronto, Ontario, M7A 2G9

Ministère du Solliciteur général | Bureau du coroner en chef | 26, rue Grenville, Toronto, (Ontario) M7A 2G9

C

October 27, 1989

Mr. Bryan Davies,
Deputy Minister of Housing,
10th Floor 777 Bay Street,
Toronto, Ontario
M5G 2E5

Dear Mr. Davies:

The Office of the Chief Coroner is currently investigating the death of Mr. This man had an eight year history of ill health characterized by a wide variety of symptoms. He consulted a number of practitioners, including a family physician, a chiropractor, a dentist and three physicians claiming special expertise in the field of clinical ecology. His diagnosis ranged from panic disorder, to temporal mandibular syndrome, to environmental hypersensitivity. Towards the end of his life he came to the conclusion that it was the latter of these disorders that was the cause of his problems.

Mr. applied for a disability pension from Community and Social Services and the application began a process where he was asked to substantiate his claim with various medical reports. It is reported that the delays and difficulties he encountered in obtaining a pension caused him considerable stress. This plus increasing family tension over his diagnosis and other matters led him to become increasingly more depressed. Ultimately, he committed suicide by means of a gunshot wound to the head. The reasons for his suicide are obviously very complex but there seems little doubt that the frustrations and problems encountered concerning his environmental hypersensitivity contributed to his ultimate demise.

Following this man's death my office has reviewed the report of the Ad Hoc Committee on Environmental Hypersentivity Disorders, the Report of the Advisory Panel on Environmental Hypersentivity and the Minister of Health's

announcement into the research project in environmental hypersentivity. In addition, there have been conversations with persons in the Ministry of Health concerning this disease entity.

The Advisory Panel's suggestion of properly studying this issue and establishing whether or not there is a scientific basis to this cluster of symptoms, seems to be a valid approach. The study announced by the Minister, therefore, seems to embark upon this road. My reading of the Advisory report, however, suggests that the other important component to the recommendations is the issue of what to do to aid these people while decisions are being made as to the scientific basis of their illness. Clearly these people are suffering and tradition in this province dictates that they are treated in a compassionate and caring manner. The Advisory Panel seems to suggest that a lay committee be established to help establish policy concerning what to do with these patients in the interim and assess potential admission to treatment facilities such as might be found in the United States. It is my understanding that to date no decision has been made as to whether or not this model will be followed. I am not suggesting that this model must or should necessarily be followed but it would seem to me that the Ministries involved need to establish some clear guidelines as to what they are prepared to provide in the way of services and benefits to the people affected by these disorders. Once such a set of guidelines is established the rules could be distributed to health care professionals throughout the province and all parties would have a clear idea of what services are available and how to go about securing them. At present there does not seem to be a clear understanding on the part of many practitioners as to what direction the province is taking in regard to this difficult issue.

I am writing to the Deputy Ministers of Health, Community and Social Services and Housing with the hope that these and any other ministries that might be concerned with this issue will begin a consultative process and help to establish some guidelines.

Thank you for your consideration of this matter.

Sincerely,

Ross C. Bennett, M.D.
Chief Coroner for Ontario

RCB/yh

Psychiatric Patient Advocate Office

Bureau du défenseur des droits des malades mentaux

8th Floor, Suncor Building, 56 Wellesley Street West, Toronto, Ontario M5S 2S3 / Telephone 927-1575 & 963-2596

July 13, 1989

Mr. Howard Danson
Acting Director
Psychiatric Hospitals Branch
Ministry of Health
15 Overlea Boulevard
Toronto, Ontario M4H 1A9

Dear Mr. Danson,

Re: Mr. Chris Brown: Environmental Factors Affecting Mental Health

Our program has been contacted by Mr. Chris Brown on several occasions regarding this issue. I understand that he has also corresponded with Mr. Jay Kaufman, and you may be preparing a response on his behalf. Our review has found that there is a growing body of knowledge indicating that some people are sensitive to agents in their environment including building materials used in residences and public buildings, cleaning products and other items such as food additives and perfumes. In some cases, the physical effects are so profound that the person's career and family relationships are in jeopardy. Mr. Brown asserts that environmental agents can also have serious central nervous system effects; that some sufferers have suicided in despair of their predicament; that these symptoms can easily be misdiagnosed as mental illness and may be treated inappropriately with neuroleptic medication.

At Mr. Brown's suggestion I have ordered and received from Health and Welfare Canada a 244 page bibliography entitled "Healthy Environments for Canadians", which I would be happy to share with you. The mainstream medical profession has often responded sceptically to claims about the effects of environment on health. Some of the claims may seem extravagant or unsubstantiated. However, it is interesting to note the number of school boards in Ontario which have recognized the extent to which a child's environmental sensitivities can affect behaviour and ability to learn.

As an alternative to the traditional responses - putting the child on high doses of medication, applying stigmatizing labels and streaming the child through special classes for those with behavioural problems and learning disabilities, these Boards have constructed "clean rooms" in some schools. These rooms are free of the agents - carpet glues, formaldehyde from particle board, mold in the ventilation system, etc. that affect some students, and the results are apparently quite positive.

Just as a child's mental and physical health and academic future can be jeopardized by failure to deal with environmental sensitivities, one can imagine equally devastating results if a person displaying a CNS response to toxins were mis-diagnosed in a psychiatric facility. Indeed, the toxins might be present in the facility, jeopardizing hope of relief.

The problem of hospital environment is not new to the Ministry. For example, there have been complaints for years that Queen Street Mental Health Centre is a "sick building". Staff there (including our own) complain of headaches and fatigue resulting from the quality of the air. The effects on patients exposed to that environment twenty-four hours a day must be more dramatic.

However, despite the potential size of the problem, we feel the Ministry should work towards raising clinicians' awareness of the effects of environmental toxins, and should have alternatives available to patients suspected of having these sensitivities. Just as diagnosis of mental illness requires the physician to investigate and rule out physical causes, head trauma or substance abuse, they should also consider CNS response to environmentsl toxins as a possible cause of the presenting symptoms. Treatment should include placing the patient in a clean room while in hospital, and discharge planning to a clean home environment.

I realize that this is an area which is going to require continuing research and creative solutions. I am circulating this letter to all Patient Advocates and requesting they inform our office of any cases in which environmental sensitivities have been an issue for patients. Our office would be pleased to assist in the development of responses to this concern.

Sincerely,

David Giuffrida

David Giuffrida
Legal Counsel

DG/dg

c.c. Mr. Chris Brown
All Patient Advocates

"...Chemical sensitivity may have physiological causes, psychological causes, or both. The search for a cause in a specific patient is most likely to lead a physician to pursue one avenue before investigating the other. Often it is only one avenue, however, that is pursued. There are two kinds of mistakes which the investigator or diagnostician could make: in pursuit of an environmental cause, true psychological causes could be ignored or, alternatively, in pursuit of a psychological cause, true environmental causes could be ignored. The consequences of making those mistakes are different. Pursuing the psychiatric route first may subject the patient to the complexities of establishing a therapeutic relationship and/or the prescribing of psychiatric drugs, and both may generate doubts of the patient's mental health. In addition, psychotherapy may be unproductive if environmental causes are at work. Labelling a patient with a psychiatric illness may be pejorative when viewed from the perspective of an employer, co-workers, and family. It is no accident that psychiatric records are kept separate from the medical records of patients. In the event that psychoactive drugs are used, any hopes of unravelling an environmental cause or contribution to the patient's underlying condition may be greatly complicated. Alternatively, if one were first to pursue the investigation of environmental causes of the illness, especially with double-blind placebo-controlled study in an environmental unit, the patient may discover an environmental cause; even if he does not, the confidence or justification with which a psychiatric etiology would be pursued is strengthened. Workup in an environmental unit is unlikely to interfere with or complicate subsequent psychiatric workup and thus the making of a mistake in choosing this option (investigating environmental causes first) can be more easily remedied.

In summary, one can remain agnostic about which route is likely to uncover the truth regarding causation, but the costs of erring are significantly different regarding the two routes of investigation. We think that these facts are sufficiently compelling to justify the investigation of environmental causes first, before committing patients to potentially detrimental psychiatric interventions, such as long-term psychodynamic psychotherapy or long-term medication. Certain cognitive behavioral therapies, short term or focused, may be beneficial but should not be relied on to the exclusion of evaluating the chemical component."

(pp C-6,7; Chemical Sensitivity, a Report to the New Jersey State Department of Health; Nicholas A. Ashford, PhD., J.D., Massachusetts Institute of Technology, and Claudia S. Miller, M.D., M.S., University of Texas; December 1989)

Minister of National Health
and Welfare

CANADA

with
the compliments of
avec
les hommages de

Charles Caccia

M.P. for Davenport

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The Honourable Charles L. Caccia, P.C., M.P.
Davenport
House of Commons
Ottawa, Ontario
K1A 0A6

Dear Charles:

Thank you for your letter of August 28, 1990, with the excerpt from the report by Drs. Ashford and Miller prepared for the New Jersey Department of Health.

This report has been reviewed by officials of my Department. Excerpts were provided for the Workshop on Environmental Sensitivities held on May 24, in Ottawa.

This is considered to be an excellent report. The authors' general conclusion that the search for environmental causes in a patient should precede psychiatric workup is fully supported by departmental officials.

Sincerely,

Perrin Beatty

Perrin Beatty

SEP 2 6 1990

Minister of National Health
and Welfare

CAN

with
the compliments of
avec
les hommages de

Charles Caccia

M.P. for Davenport

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The Honourable Charles L. Caccia, P.C., M.P.
Davenport
House of Commons
Ottawa, Ontario
K1A 0A6

Dear Charles:

Thank you for your letter of October 25, 1990, requesting clarification on actions which reflect my Department's support for the environmental sensitivity issue.

Following a Workshop on Environmental Sensitivities held in May of this year, my Department prepared a Publication of the Proceedings which will be available as soon as the French version is completed. These proceedings include a recommendation supporting the conclusion referred to by Ashford & Miller regarding the need to search for environmental causes prior to psychiatric workup in a particular case. It is proposed to publicize these recommendations widely with the aim of helping to educate physicians and the public.

Thank you for your interest in this matter. I hope that the foregoing information will prove useful to you.

Sincerely,

Perrin Beatty

Ottawa, Canada K1A 0K9

DEC 17 1990

Behaviour problems linked to environment

Food and other substances can directly affect children's behavior, to the point of determining their success or failure in school, says an Ontario psychologist.

Traditional beliefs about physical and mental health need overhauling, says Dr. Jeff Phillips, clinical supervisor at North Bay's Concordia Children's Mental Health Centre. Children "labelled as having psychological problems" often suffer severe environmental sensitivities that go untreated

In a recent issue of *Education Today*, Phillips poses these questions to teachers who've despaired of hyperactive or sullen students:

"What kind of behavior did you observe on the last Hot Dog Day or during your school's latest chocolate bar sales blitz? How many of your students just don't seem to be able to attend or concentrate? How about the student with the attitude problem that no one can explain?"

He suggests they examine their own mood swings next time a nearby room is painted, or roof is tarred.

Common food substances that can skew sensitive metabolisms include: cow's milk, corn chips, dextrose, beers, whisky, the pea family, tomatoes, cinnamon, sugar, beef, yeast, garlic, fish, bananas, soy products, eggs (mayonnaise, breads, icings, noodles), citrus fruits, wheat (other commonly eaten grains), food additives (preservatives, coloring, etc.), pork, shrimp, onions, white potatoes, coffee and pecans.

Foods rarely sparking reactions include: organically grown products; such vegetables as beets, spinach, cabbage, cauliflower, broccoli, turnips, brussel sprouts, squash, lettuce, carrots, celery, sweet potatoes; such fruits as plums, cranberries, blueberries, gooseberries, currants, apricots; and such meats as chicken, turkey, lamb and rabbit.

As long as we ignore the effects of diet, many children will continue to suffer mistaken diagnoses that only compound their problems, Phillips says.

Phillips cites the example of a young patient "first presented as unusually aggressive and hyperactive. Her mother indicated that no one had ever seen her smile and that she consistently failed to respond to adult requests or discipline."

Among the mistaken diagnoses, the mother had been accused of insufficiently bonding with the girl. The strain of such remarks, in what was in fact "a very positive family (with) bonding galore," was wearing down the parents' marriage.

Phillips ushered the girl to a clinical ecologist – who immediately found she had severe immune system problems.

Once treated for these, the girl calmed down, and grew more cheerful and sociable. Such improvements are always reflected in school performance, says Phillips: "It is not uncommon for clients to report increases in school grades of 10 to 40 per cent and sometimes more."

He lauds the Waterloo County Board of Education for taking heed of the link between environment and behavior. Waterloo has built "two environmentally clean classrooms for ... students identified as having both environmental sensitivities and learning or behavior problems."

In these classrooms, sophisticated air filtration, nontoxic materials, all-wood furniture, and a strict ban on chemicals ensure a hazard-free chance for learning, he explains.

Not all boards can outfit such rooms right away, but Phillips hopes educators will become informed about environmental dangers. "School personnel are in an ideal position to observe students and note symptoms...of environmental sensitivity related to learning or behaving problems."

They can teach students the same awareness. One Toronto teacher inspired her class to demand that the local McDonald's banish polystyrene containers. The restaurant now serves burgers on paper napkins.

"This is a great start and it only took the resources of one teacher and her students. Just imagine what an entire system could do if mobilized."

BCSTA

EDUCATION LEADER is published by the British Columbia School Trustees Association.

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Our promise to readers – *Education Leader*: useful information about broad curriculum and policy issues and developments, and the latest in trends and research – if it isn't important to schools, it doesn't see print.

Living

Food behind boy's hyperactivity

CALGARY (CP) — It seemed that nothing could slow down seven-year-old Nathan Hunt. The Calgary boy seemed stuck in permanent overdrive and it was pushing his mother, Maureen, to the brink of despair.

But a study of foods and the effects they had on 24 hyperactive boys changed the Hunts' life.

The food study, sponsored by Alberta Children's Hospital, found that 50 per cent of parents reported a change of diet improved the behavior of their children half of the time.

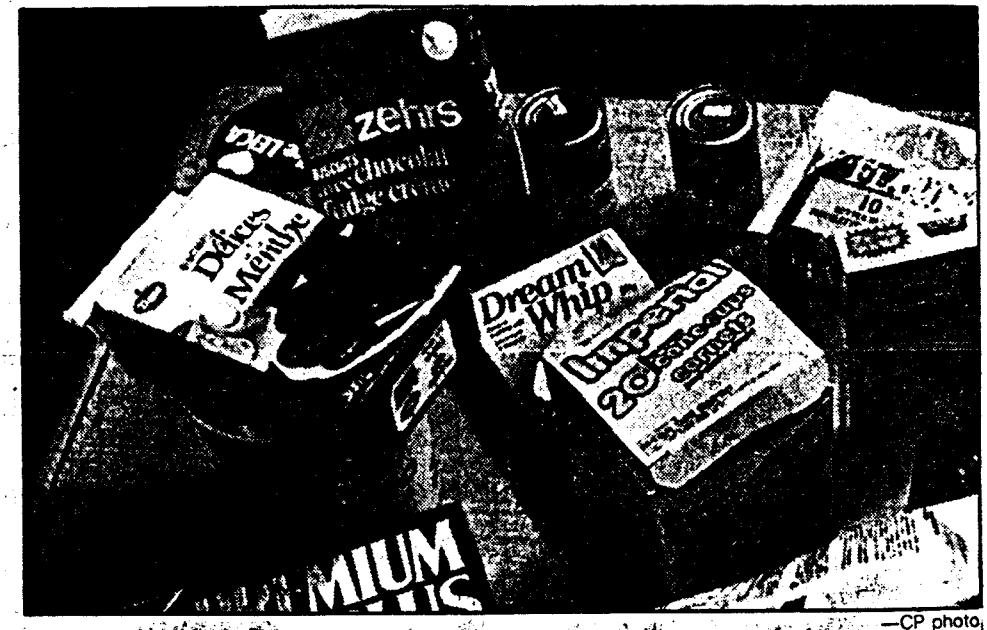
Dr. Bonnie Kaplan, director of behavior research at the hospital, has been exploring the ways people react to food for almost a decade. In effect, she's been checking to see how much truth is behind the saying, "You are what you eat."

Her research team concentrated on foods loaded with preservatives, food coloring, and artificial flavors or aromas and measured the way those foods affected the behavior of the 24 young boys.

For the families among the fortunate 50 per cent, the food study became a major turning point. The parents have learned how to regulate their son's activity level by ensuring they don't eat foods containing high amounts of preservatives and artificial flavors.

The change for Nathan came during the food study. When he ate foods without additives and preservatives, he slowed down. He was finally able to concentrate at school. He slept better.

"Even when Nathan was asleep he was active," recalled Maureen Hunt. "He'd toss and turn in his sleep, and he'd cry and mumble. I remember he'd sleep with his fists clenched. Even after I'd pry them open, they'd recoil again."



—CP photo

Junk food: A lot of junk food contains preservatives, additives

Waking up at night was common for Nathan. During the food study, Maureen kept count — one night he woke up 20 times.

As a preschooler, he would race through the house. He'd do it "for what seemed to be hours. Sometimes we'd tell him to change directions so he wouldn't get dizzy," she recalled.

He threw things. He broke family treasures. Once he tried to climb into a fireplace but was stopped before he burned himself. His body seemed to move faster than his brain.

She often ended up weeping in despair, wondering what was wrong. She became afraid to go out with Nathan. She hated the nasty looks she got when he'd pull down a supermarket display. Friends, family members and neighbors couldn't help suggesting her son needed some discipline.

Since the study, she's avoided preservatives and additives, and spent a lot of time at the supermarket reading labels. Still, every once in a while Nathan, now seven, will trade part of his lunch at school.

If he gets something with additives in return — a store-bought cookie, a flavored drink, or candy — he'll be a speedy wreck when he gets home.

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Ontario

LEGISLATIVE ASSEMBLY

David Reville, MPP
Riverdale

OPEN LETTER

March 14, 1989

The Honourable Elinor Caplan
Minister of Health
10th Floor, Hepburn Block
Queen's Park

Dear Mrs. Caplan:

I am writing to express my grave concerns about the inaction on the part of your government to assist the current needs of Ontario citizens suffering from severe and sometimes even life-threatening environmental sensitivities.

It is now three and a half years since the Ad Hoc Committee on Environmental Hypersensitivity Disorders, chaired by former Judge George Thomson, reported to your Ministry. I think it is fair to say that Judge Thomson's committee found that environmental sensitivities do exist and that Ontarians who suffer from such disorders have a tremendous need for medical and social support.

I applaud the February 10 announcement that your Ministry will be providing some $600,000 for research into sensitivities caused by foods or chemical contaminants in foods. But while that initiative is laudable, it does nothing to address the current needs of environmentally sensitive people, using the medical information and social supports that **already** exist.

The reality of environmental sensitivity disorders is recognized in the medical community. In a recent letter to the Premier's Office, John Krauser of the Ontario Medical Association wrote: "The situation is that individuals are ill with a condition that has not been scientifically defined and they are not being well served in their need for support services. This situation is clearly frustrating for patients, physicians and government and requires careful attention to avoid blaming the victim.... There is widespread support for efforts to improve the ability of practising physicians to treat these patients."

While research is being conducted, your government should be doing whatever possible now to assist those

. . . over

suffering from the lack of support from the province for environmentally sensitive people. Actions could include the following:

o Initiatives should be taken by the government to construct housing for the environmentally sensitive that is free of construction materials which cause toxic reactions.

o Reasonable accomodation in workplaces should be afforded to the environmentally sensitive.

o Those who require special diets that are a significant financial burden on the individual should receive assistance.

o O.H.I.P. should pay the medical costs of all Ontario residents needing out-of-province treatment for environmental sensitivities when these medical services are not available in Ontario. Nova Scotia has taken this action for several patients in that province.

o The Minsitry of Health should follow the lead of the government of Nova Scotia in funding one or more Ontario physicians to take training in the treatment of environmentally sensitive patients in other countries, for example in England.

Ontarians suffering from environmental sensitivities are frustrated at provincial inaction since Judge Thomson's 1985 report. While research may lead to help years down the road, it does nothing to address their daily needs right now. I would appreciate your outlining the steps beyond research that the government will be taking to help those Ontarians suffering from these debilitating illnesses.

Sincerely,

David Reville, MPP
Riverdale

c.c. The Hon. John Sweeney, Minister of Community and Social Services
The Hon. James Bradley, Minister of the Environment
The Hon. Chaviva Hosek, Minister of Housing
Mr. Raj Anand, Ontario Human Rights Commission

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THE LAW SOCIETY OF UPPER CANADA

OSGOODE HALL
TORONTO, CANADA
M5H 2N6

September 14, 1988

Mr. Chris Brown
1102-258 Lisgar
Ottawa, Ontario
K2P OC9

Dear Mr. Brown:

Thank you for the extensive material that you have sent to me that I have only now finished reading, as I was heavily involved in getting the social assistance report ready for release last week.

I think I should begin by telling you that I too, have been concerned that we have put extensive effort into a new report for the Government at a time when the recommendations of the earlier report I was involved in have generally not been acted upon. When the Social Assistance Review Committee was created, there had been some delay but it did not appear that the Government was not going to act on those recommendations. The Minister for whom we did the social assistance report is, we think, a very committed individual and it was his assurances that this would not be an ignored report that led all of us to take on the job. As well, the social assistance report did give me an opportunity to address some issues that are of importance to those with environmental hypersensitivity, e.g., the definition of disability for the purposes of social assistance.

None of this takes away the fact that I have been and remain very disappointed with the response to the report on environmental hypersensitivity. I have been as vocal as I can be about the need to implement the report, including being available for any public discussions of the issue and meeting with the Minister of Health, the Deputy Minister and other people within the Health Ministry. I remain convinced that our recommendations make sense and would do much to diffuse the adversarial atmosphere that makes things worse rather than better for patients. The fact that I am now part of a second report for government in no way diminishes my concern in this area.

I am most impressed with the work that you have been doing to bring the issue to public attention. I would be quite prepared to meet with you when I am next in Ottawa to talk about what kind of help I could be. If you are interested, perhaps you might call me (461-947-3414) and we can set up something.

I told the press last week that I release this report with some trepidation because of what was done with the earlier report. However I also feel very strongly that major changes must occur in the social assistance system and so I am prepared to fight hard for those as well. I hope you are not right in your suggestion that the earlier results make this effort somewhat of a sham. Only time will tell.

I look forward to talking with you further.

Yours very truly

George M. Thomson

GMT:GG

Ottawa Citizen 16 April 1991

Asthma: Burying myths of chronic illness

ARNOLD RINCOVER

PSYCHOLOGY

In 1965, Eysenck, an English researcher, described a famous case of psychologically induced asthma.

The patient was a married man who didn't get along with his mother-in-law. A large picture of her hung over the bed in the bedroom, at the insistence of his wife. Eysenck reported that when the mother-in-law's face was turned toward the wall, the man's asthmatic attacks immediately stopped.

They could be brought back at will simply by turning the picture again, and then terminated by turning her face to the wall once more.

This case study did little to help relations with in-laws, and it did even less for asthmatics. People began thinking that asthma was due to disturbed relationships or personalities, which we now know isn't true.

How myths begin

It is unfortunate that people didn't recognize at the time that this case study was published because it was so unusual, not because anyone thought it was in any way representative or typical of asthmatics. Still, this is how folklore and mythology begin.

Some studies have looked at the personal lives of asthmatic children. Lo and behold, they found many so-called neurotic symptoms: dependency, anxiety, maladjustment, obsessions, etc. So, asthmatics must be neurotic, right?

Wrong! This is how the ugly, harmful myth probably started. This notion has been hard to erase over many years, and I hope that the following explanation will help give this unfair and destructive notion a quick burial.

Subsequent research has clearly shown that most children with a prolonged illness show more problem signs than healthy children — excessive anxiety, dependency, obsessions about health, etc. — and this simply reflects a normal reaction to a prolonged illness.

The same difficulties have been found for children with other chronic illnesses. Dependency, anxiety, obsessions about health, etc. are always higher the longer the patient has been sick.

In no study has there been any evidence that personality problems played a role in the development or maintenance of asthma.

Instead, some difficulties may arise as a result of asthma, and these difficulties are no more or less than you and I would show if we were burdened with a chronic illness.

While there is no evidence for any role of personality problems in the development of asthma, this does not mean that psychology does not play a role.

Studies have shown that even when the asthma was caused by infection or allergy, psychological stress or suggestion can precipitate an attack.

Pollution study

In one such study, 40 asthmatics participated in a "study on air pollution." The asthmatics were each told that they were going to inhale a substance that earlier had been found to be an irritant or allergen for them. In fact, it was a placebo (a saline solution), which could not cause any harm.

Twelve of the asthmatics developed significant respiratory problems when they inhaled the placebo.

Later, they were told to inhale another solution that was a medicine (a "bronchodilator"); in fact, it was the very same solution. The breathing of each patient improved, confirming the role of suggestion in some asthmatics.

Even here, however, it is important to emphasize that for the large majority (28 to 40) of patients, the power of suggestion was low or nonexistent.

In a similar way, other psychological variables such as stress, anger and fear can play a role in asthma, when they overwork or irritate an already sensitive or ailing respiratory system.

NOTE: The Lung Association is holding a one-day seminar, "Children With Asthma: Understanding Your Wheezing Child," in conjunction with the Children's Hospital of Eastern Ontario on May 4 at 9 a.m. at the University of Ottawa Health Sciences Centre, 451 Smyth Rd.

The seminar costs $30 a person. For registration information call Melanie Carkner at 728-4649.

Arnold Rincover is a registered psychologist, author of *The Parent-Child Connection* (Random House), and associate professor at the University of Toronto. This column is not intended to provide treatment and anyone concerned about a psychological problem should seek professional assistance. Readers can write to Dr. Rincover c/o the Citizen, P.O. Box 5020, 1101 Baxter Rd., Ottawa, Ont. K2C 3M4.